

## **Family News**

June 2003

News and Information for Families of individuals at Muscatatuck SDC and Madison State Hospital during the transition to community-based services.

## Independent Study Released! Survey Results Reflect Satisfaction

Nearly 90 percent of surveyed families of former Muscatatuck State Developmental Center residents are happier with their loved ones living in the community, according to a recently released independent study. The study, conducted by researchers at the Indiana University Institute on Disability and Community, surveyed families of people who have moved from Muscatatuck in the last two years. The new results were even more positive than last year, when 71 percent of families said life in the community was better for their loved one than life in an institution. This year, 89 percent of families said community life was better.

The families expressed pleasant surprise at how quickly their loved ones adjusted to the move and their new environment.

John Hamilton, Secretary of the Family and Social Services Administration, hailed the study as proof that helping people with disabilities live in the community allows them to thrive.

"This study reinforces what many people with disabilities already know: that they'll be happier in

the community than in an institution, and they can thrive as active members of those communities," Hamilton said. "With appropriate support and care, they can shop

## Secretary Hamilton Responds To Your Questions

- ⚠ How do things differ now for consumers of state operated facilities (SOF) that are closing as compared to the resources and transitioning services available when Central State Hospital closed? Have there been significant changes in the state standard operating procedures for transitioning consumers from state operated facilities to home or community-based care?
- According to Dr. Eric R. Wright, Associate Professor of Sociology at IUPUI and Project Director for the evaluation project, when Central State Hospital (CSH) was closed, the Indiana Division of Mental Health and Addiction (DMHA) put in place three important structures to ensure that adequate resources were available for consumers in the community. First, a coordinating committee of staff from CSH and community agencies was created to discuss and plan each consumer's transition. Second, DMHA created a "community transition fund," funded in part by the decline in the hospital's operating costs during the transition period, to provide money to community providers to cover start-up costs associated with creating new programs and/or new facilities to receive the consumers. Finally, contracts were written between DMHA and specific providers who agreed to accept the former CSH consumers. This had the effect

(Continued on page 2)

(Q & A, continued from page 1)

of making sure that funds originally provided for the consumers' hospital care followed them to community settings. In the research group's comparison of the CSH experience with other closure/down-sizing initiatives, these structures appear to have been critical factors in the success of the overall transition process.

The person-centered planning process for consumers being discharged from Muscatatuck State Developmental Center and Madison State Hospital relies on a similar planning strategy. This effort seeks out providers who can meet individual consumers' needs and specify how they will provide these services in the community.

- Do many consumers who leave a stateoperated facility return to a SOF? If so, for what reasons and what is the process?
- A In July 1994, the first month after CSH was closed, 30.6% of the former CSH consumers were living in a SOF. In contrast, in July of 2002, only 8.5% resided in a SOF. More importantly, data indicates that these percentages were not the same set of individuals and that the large majority of consumers have had some tenure in a community setting during the past eight years. In many cases, consumers who were discharged to the community returned to a SOF because of their illness and because community mental health center (CMHC) staff felt they needed more extensive hospital care than could be provided in acute care hospital settings. It is also clear that community providers have dramatically changed the way they use SOFs. They are placing far fewer people (including former CSH consumers) in SOFs for three reasons.
- 1. There are fewer beds within the SOF

(Continued on page 3)

(Independent Study, continued from page 1)

for food, attend concerts and work in jobs. This survey helps confirm our belief that the 151 residents still at Muscatatuck will live better and happier within a community. That's why we're committed to providing the same quality of care in community settings and working with families to

More than half said they are seeing their loved one more often.

transition loved ones into the community."
About 125 former
Muscatatuck residents have moved into homes and communities across the state.
The new IU study surveyed the same 30 families used in last year's study, plus 36 additional families whose loved one left Muscatatuck in

2002. Most of the 66 respondents were pleased or very pleased with the quality of their loved one's life in the community. Their comments, according to the report, included: more involvement in the community, ability to make own choices, living environment is more like a home, better health, better attitude, gets out to do more activities and more like himself. The main negatives expressed were worries about medical issues, including access to medical care.

The families expressed pleasant surprise at how quickly their loved ones adjusted to the move and their new environment – in one case even a woman institutionalized for more than 30 years. Some noted their loved one was much easier to get along with since the move and was more capable than the parent had realized. More than half said they are seeing their loved one more often. The survey also indicates that life in the community continues to improve over time.

(Continued on page 3)

## Message From Nikki Morrell

The official groundbreaking for Indiana's first regional center was held on June 2. Thank you to all who made this possible. The center will serve as an anchor for regional services, but will not be the only location for services. Regional services will be provided in many different locations, ensuring local availability to those in need. Keeping people in their communities is FSSA's overarching approach to providing necessary services. Regionalization will help in unifying providers to increase the integration of FSSA services provision, and is expected to also reduce the burden of lengthy travel to services for consumers and families.



Pictured left to right State Senator Jim Lewis, Madison Mayor Al Huntington, Governor's Representative Andrew Stoner, State Representative Markt Lytle, FSSA Secretary John Hamilton, State Office Building Commission Director Susan Williams, and Director Southeast Region Nikki Morrell

(Q & A, continued from page 2) **System.** 

- 2. Communities now have more programs for intensive care.
- 3. Community and SOF staff face greater pressure to use the state hospitals only when community-based options don't work for a consumer.

In the past, SOFs were more likely to be used as long-term residential care settings, but today stays in SOFs are significantly shorter and focused on discrete and well-defined clinical treatment.

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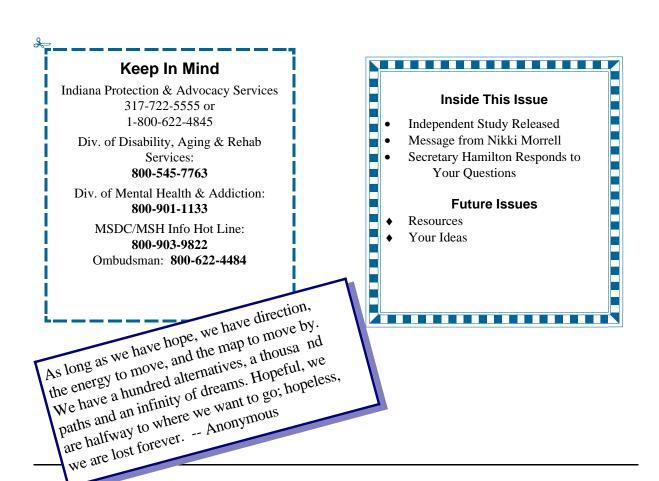
(Look for more answers to your questions about those transitioned from SOFs into home and community-based care in future issues.)

(Independent Study, continued from page 2)

Although parents were generally satisfied with the care and treatment of their loved ones at Muscatatuck, they were more pleased with their loved ones' lives afterward. The families were overwhelmingly satisfied with having been kept well informed about the transition, knowing whom to call and having their questions answered. When asked what they would advise other families with loved ones at Muscatatuck, families most commonly said to take a chance, because they would be pleasantly surprised.

View the full report at: http://www.in.gov/fssa/transition/index.html





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